

Rationing—Missing Ingredient in Health Care Reform

ERNLÉ W. D. YOUNG, PhD, *Stanford, California*

A patient in a cardiac intensive care unit used 750 units of blood in the five days between his surgical procedure and his death. His initial surgical procedure lasted 17 hours because of profuse bleeding. After two hours in the intensive care unit, he was taken back into the operating room for another five hours. When he again came to the intensive care unit, his surgeons were still unable to staunch his bleeding, yet continued to order infusions of blood.

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A patient has again gone into liver failure after receiving a second transplanted liver; now only a third liver transplantation can save her life. No one knows why the two previous transplants failed. She does not have hepatitis B, which would automatically disqualify her from liver transplantation, but she does have symptoms similar to those expected with hepatitis B. Ought she to receive a third liver transplant?

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A 26-year-old woman, a Medicaid patient who had been on hemodialysis for end-stage renal disease since 1989, had a cardiopulmonary arrest. The resuscitation attempt lasted for more than 45 minutes. By the time her heart was beating again, she had extensive, permanent, and irreversible brain damage. Neurologic tests subsequently determined her to be neocortically dead, and she was pronounced to be in a persistent vegetative state. Nevertheless, her family insists on continued hemodialysis and threatens to sue her physicians and the hospital if the family's demands are not met. A year later, she is still receiving hemodialysis three times a week.

Although American medicine is in many ways the finest in the world, from an ethical perspective our health care system (or nonsystem) has been subject to legitimate criticism on three counts: cost, unequal access, and uneven quality.

We have dodged these issues for decades, but there are now several proposals for reform. How adequately do they respond to these ethical concerns about cost, access, and quality?

Providing universal access to medical care is the right thing to do, not merely from an ethical perspective, but also from the standpoint of economics. If the uninsured, the uninsurable, and the underinsured have had no direct access to the system, they have had indirect access to it after they have become so sick as to require treatment on an emergency basis. Emergency department care is costlier than routine, timely, proactive, preventive, and health maintenance services.¹ The burden of meeting these higher costs has fallen on society as a whole, contributing to spiraling inflation in the health care sector. For insisting that health care reform include universal coverage and that it provide all citizens with the security of knowing that their health care benefits cannot be lost, no matter what may happen to their jobs, the Clinton Administration is to be commended.

I am skeptical that any of the plans can effectively hold down costs, for one important reason: all the proposals fail to admit the need for rationing. If national health care expenditures are to be held rigidly within a global budget, and if every American is to be afforded health care benefits, then we cannot all have everything we want in the way of medical services. Within a finite budget, it is impossible to satisfy both objectives of utilitarianism—providing the greatest good for the greatest number. If the emphasis is to be on the greatest number, the “good” to be offered necessarily must be limited. Conversely, if the emphasis is on providing the greatest possible “good,” then the number of those eligible to receive what is provided will have to be reduced.

Theoretically, “utility” or “the good” is not precisely defined. In practice, the theoretical notion of utility translates into tangible goods and services. Medical care is among these.

The state of Oregon squarely faced up to this. The aim was to increase the number of Oregonians eligible to receive medical treatments through the state's Medicaid program by covering all persons up to the poverty line. The legislature recognized that, operating within a fixed Medicaid budget, those to be covered could not have all the medical services they wanted. They could have only

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From the Departments of Medicine and Pediatrics (Ethics), Stanford University School of Medicine, Stanford, and Stanford University Center for Bioethics and the Palo Alto Department of Veterans Affairs Medical Center, Palo Alto, California.

Reprint requests to Ernle W. D. Young, PhD, Stanford University Center for Biomedical Ethics, 701B Welch Rd, Ste 222, Palo Alto, CA 94304.

what the state could afford. Medical procedures were ranked according to priorities determined by the three criteria of cost-effectiveness, quality-adjusted life years, and the expressed values of the people of Oregon. The state then went down this list as far as it could until its resources had been expended. Services below this line were not to be available.^{2,3}

Thirty bioethicists were invited to participate in the last two months of the discussions leading up to the speech President Clinton delivered to a joint session of Congress in which he outlined the objectives of his health care reform proposal. They were expressly instructed not to consider rationing.⁴ There was to be no recognition of the elementary fact that in a system of universal coverage that is operating within a fixed budget, hard choices will have to be made about what services are to be available, when, and for whom.

Compounding this fatal flaw in the proposals now beginning to be debated in Congress is the way the word "quality" seems to be used as a synonym for "quantity." The quality of the present system must be and will be maintained, we are told. Translated, this means that we will continue to receive whatever we have become accustomed to. There will be no cutting back on the array of services to be provided.

Underlying this deliberate avoidance of the subject of rationing, or any discussion of limits, is a political capitulation to a popular misconception of the nature of autonomy. In the writings of John Stuart Mill and Immanuel Kant, autonomy is construed as a negative right to noninterference in matters of personal choice and private self-determination—with the sole proviso that one's choices ought not to harm or endanger others.⁵ What began as a negative right to noninterference has commonly come to be thought of as a positive entitlement—the right to have whatever we want, especially if someone else is paying for it. Rather than the current proposals for health care reform challenging this distortion of the original meaning of autonomy, they accommodate it.

Limits must be considered if costs are to be held down and universal access to the system is to be guaranteed. Quality can and must be maintained, but not quantity. Marginally beneficial or useless treatments are inimical to quality medical care. Yet these are what patients, their families, or their physicians often want. Autonomy, misconstrued, cannot subvert the principle of distributive justice.

If the three goals of holding down costs, including all Americans in the health care system, and assuring quality are to be met, the three patients described at the beginning of my article would not receive the care they did. Yet another example is to be found in neonatology. In neonatal intensive care units, we continue aggressively to treat infants weighing less than 750 grams at birth, whose gestational age is barely 24 to 26 weeks. This is exorbitantly costly, and the results are not encouraging. Only about a third of these infants survive; of those who do survive, about 50% are moderately to profoundly damaged—neurologically as well as physiologically. Will intensive care

for this category of infants continue to be available in a system of universal access within a global budget? Or, as I have argued,⁶ ought this to be designated and funded as research and offered only to a limited number of patients on an experimental basis?

For refusing to consider or to allow the consideration of rationing, the current proposals fail. But the failure is not the politicians' alone. They are merely responding to what they perceive to be the will of the American people. Ultimately, the failure is ours. Daniel Callahan puts his finger on it:

What might be called the death fallacy—the notion that our mortality should be wholly under our control—has two components, one moral, the other medical. The moral part is the belief that we have an unlimited obligation to combat death and lethal disease. . . . The medical part is the potent assumption that death is essentially an accident, correctable with enough money, will, and scientific ingenuity. . . . In other industrial countries neither a very-low-birth-weight baby nor a seriously ill elderly person is likely to be subjected to aggressive treatment. They have made the judgment that in certain cases the price of continued treatment is simply too burdensome to the patient and to society ("Our Fear of Dying," *Newsweek*, October 4, 1993, p 67).

We have failed to make that judgment. Until we do, the laudable goals of simultaneously holding down medical expenditures, ensuring universal access to the system, and maintaining its quality will continue to elude us.

This leads to the hard questions: by what ethical criteria and by what methods can services be limited? As a basis for further discussion, let me respond briefly to these two questions.

Ethical Criteria for Limiting Services

We have to learn to distinguish needs from wants. It was perhaps easier for the British to do this when the National Health Service was launched in 1948 than it is for us now in 1994. Before 1948, the British had fought a long, debilitating war from 1939 to 1945. During these years, rationing of food, fuel, and clothing was commonly accepted. Austerity did not end with the war. The postwar years required a British contribution to the rebuilding of Europe. The available resources were needed to provide necessities; little was left over for luxuries.

Our situation in 1994 is vastly different. In 1959, when the Stanford Medical Center moved from San Francisco to the main campus and a new hospital was opened, it did not have a single intensive care bed. Today there are more than 200. The 1960s, 1970s, and 1980s saw the expansion of high-technology, high-cost intensive care medicine in the United States. Luxuries came to be thought of as necessities. Wants came to be equated with needs. Drawing a distinction between the two categories as we embark on a new health care system is clearly much more daunting a task for us than it was for the British in 1948. Nevertheless, this is the challenge we all now face—not only in health, but also in such areas as transportation, education, and housing.

Even if we were able to distinguish between needs and wants (perhaps the first criterion for rationing), we are left with a further difficulty. Because of what might be called the genetic and social lotteries, people have widely

differing medical needs. How might those with exceptional medical needs be justly served if rationing is inevitable? Distributive justice is at issue here. Any plan to limit services must be consistent with this cardinal ethical principle.

My most radical criticism of the current proposals for health care reform is that they are predicated on universal access to the same basic package of benefits for all—a single-tier system.

Perhaps what is needed is a three-tier system consisting of the following:

- Universal access to basic medical services, with the emphasis on primary care, preventive medicine, and health promotion.
- Access to a more limited array of medical, surgical, and psychiatric services for those with exceptional or catastrophic needs caused by the genetic and social lotteries.
- Supplemental services not included in the basic package and not qualifying as catastrophic that could be purchased through insurance by those who can afford to do this.

Only then will people be fairly treated, according to need.

Defining basic medical services and services for exceptional or catastrophic needs will be the challenge. How might this be done? Before addressing that question, let me remark on what I consider to be an ethically unacceptable criterion for rationing, that of chronologic age.

A number of writers find age an attractive standard for rationing.^{7,9} The popular argument is that in Britain, under the National Health Service, persons older than 55 years are not eligible for regular hemodialysis or for renal transplantation. Why should we not ration services in the same way?

It is not true that in the United Kingdom age is the basis for rationing. There is no policy limiting the use of long-term hemodialysis and renal transplantation to persons younger than 55. General practitioners decide whether or not to recommend persons older than 55 for these services on the basis of an assessment of their patients' overall health and the availability of resources in the region. It is true that the recommendation for dialysis or transplantation generally is not made for older patients.

Physiologic reserve (the health and vitality of the major organ systems added up and taken together) rather than chronologic age is a sounder criterion for rationing costly services. Persons in their 40s may have little physiologic reserve. Conversely, there are those in their 80s whose physiologic reserve is considerable. No moral objection can be made to physiologic reserve being used as a criterion for admission to intensive care units or to determine eligibility for other high-cost, high-technology, acute medical services.

Methods for Limiting Services

Demographics and epidemiology will be important in the attempt to limit services. Both disciplines can provide indications of the principal needs of the population gen-

erally, as a guide to setting priorities. Beyond this, there is much to learn from the Oregon experiment. Better outcome data—both for efficacy and cost—for common as well as uncommon interventions are necessary. Estimates of improved morbidity and mortality resulting from various interventions can and must be made. The concept of quality-adjusted life years may be a first step in the right direction. And the American people have to be involved in the process of ranking services according to their own preferences and values. Only as citizens share in formulating health policy proposals through a democratic process of participation in surveys, questionnaires, and town meetings can they be expected to accept and abide by the limits that eventually are established.

A further urgent imperative is that the medical profession must begin more rigorously to define appropriate standards of care in various diagnostic categories. The examples I gave at the beginning of this article illustrate what will not be possible if the three goals of affording universal access, holding down costs, and assuring quality are to be met:

- The high-risk cardiovascular surgery patient who received 750 units of blood in the five days before he died had been turned down by two other medical centers before being accepted by a third. This suggests that selection criteria for high-risk procedures need to be more carefully defined nationally and applied locally.

- Assuming that liver transplantation is included in a list of priorities for services available to those with catastrophic needs, how many organs should a single patient receive? Ought this decision be made on the basis of past investment in a given patient or on the unmet needs of others awaiting transplantation? Those doing transplantations must address this issue at a policy level.

- What is the standard of care for patients in a persistent vegetative state? There is no medically agreed-on answer to this question. Hence, a nephrologist who believes hemodialysis for such a patient to be inappropriate is out on a limb—subject to the threats and manipulations of family members whose wants are being denied. Here, too, the profession must back physicians attempting to make hard choices by developing a more universal consensus about what is and what is not medically appropriate.^{10,11}

- Whether neonatal intensive care continues to be available for infants weighing less than 750 grams with a gestational age of 24 to 26 weeks also needs to be decided by subspecialists in this field after an informed and deliberate review of the outcome data at the national level.

Rationing is possible, and it can be done ethically. It will require acceptance of a three-tier system of medical services. Which services qualify as basic and which as catastrophic will have to be decided on the basis of demographic, epidemiologic, and outcome data; estimates of quality-adjusted life years; the values and preferences of the American people; and last, but not least, the medical profession defining the limits of appropriate treatments in various diagnostic categories.

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